

## Overcoming Barriers and the Stigma Associated with Mental Illness in American Indian and Alaska Native (Al/AN) Communities

June 23, 2005



#### **Sponsor**

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The ADS Center provides practical assistance in designing and implementing anti-stigma and anti-discrimination initiatives by gathering and maintaining best-practice information policies, research, and programs to counter stigma and discrimination. We actively disseminate anti-stigma and anti-discrimination information and practices to individuals, States, local communities, and public and private organizations.



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The Moderator for this call is Michelle Hicks



#### **Questions?**

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#### **Speakers**

#### **CDR R. Andrew Hunt**

Andy is a member of the Lumbee Tribe of North Carolina. From 1991-2000, through a series of assignments with the Indian Health Service he provided direct mental health counseling and, managed a tribal mental health program in the Pacific Northwest. Since 2000 Andy has been assigned to the National Indian Child Welfare Association (NICWA) in Portland, Oregon. He directs and provides technical assistance to Indian communities that receive systems of care funding. In 2003, Andy was the first Native American to receive the U.S. Public Health Service Social Worker of the Year Award, presented by the Surgeon General.



#### **Speakers**

#### **Donna Grandbois**

Donna Grandbois is a Clinical Instructor in Psychiatric/Mental Health Nursing and The Family in the Community Case Management course at the University of North Dakota. She graduated cum laude from the University of North Dakota with a Bachelor of Science degree in Nursing and a Master of Science degree which focused on rural health with an emphasis in psychiatric/mental health nursing. She frequently makes professional presentations on policy issues that tend to restrict American rural mental health services and mental health providers' responsiveness to American Indian clients. Ms. Grandbois is a member of the Turtle Mountain Chippewa tribe and has received numerous awards and scholarships.



#### **Speakers**

#### **Daniel Bill**

Daniel Bill is the Village Clinical Supervisor for the masters level clinicians and paraprofessionals. He has many years experience in clinical services as a mental health and substance abuse service provider. He is employed by the Yukon-Kuskokwim Health Corporation which provides services to fifty-six villages. He works with other mental health and substance abuse professionals in providing services to persons suffering from mental Illness and substance abusers. His primary objective is to provide services at home or as close to home as possible. He is an Alaska Native who works with his fellow Yupik natives and in most cases utilizes the traditional native perspectives toward improving and healing. He is a graduate of University of Utah's Graduate School of Social Work.



# American Indian/Alaska Native perspectives on mental health stigma

Andy Hunt, MSW, LICSW

Director of Community Development for Children's Mental Health National Indian Child Welfare Association

Resource Center to Address Discrimination and Stigma
Web-Conference
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### Diversity of Native population

- 4.1 million people reported as Al/AN in 2000 Census
  - 2.5 million as Al/AN only
  - 1.6 million as Al/AN and other race
- 563 Federally Recognized Tribes
- 245 Non-Federally Recognized Tribes petitioning for recognition
- 34 Urban Indian Health Programs contracted with the Indian Health Service (IHS)
- Urban Indian Centers in at least 26 states

### Concepts of Mental Health

- Traditional Native worldviews of "mental health" are based in a balance between body, mind, emotion and spirit
- Individual "mental health" is related to the health and balance of the extended family and the overall community context
- Western medical model/linear worldview concepts of "mental health" have been introduced and tend to create and reinforce stigma in Native communities

#### Lessons from the Field

- Two major children's mental health initiatives that have had significant tribal involvement
- One goal of the "systems of care" initiatives is the reduction of stigma
- Center for Mental Health Services (CMHS)
  - Circles of Care 3 year planning grants for tribes and Urban Indian organizations to develop infrastructure for systems of care
  - Child Mental Health Initiative 6 year implementation grant to develop systems of care for children

#### Circles of Care efforts

- Community-based planning meetings
- Focus groups and key informant Interviews
- Family member advocacy
- Community-based definitions for "Severe Emotional Disturbance"
  - Most communities had a variation on the them of a youth who is "out of balance"
- Strengths-based approaches

#### Circles of Care I 1998-2001

- Cheyenne River Sioux Tribe S.D.
- Feather River Tribal Health CA
- Shared Vision Project MT
- First Nations Community Healthsource N.M.
- Oglala Sioux Tribe S.D.
- Choctaw Nation of Oklahoma
- Urban Indian Health Board Oakland, CA
- Fairbanks Native Association- AK
- Inter-Tribal Council of Michigan

#### Circles of Care II 2001-2004

- Tlingit and Haida Tribes AK
- Pascua Yaqui Tribe AZ
- Salt River Pima-Maricopa Indian Community AZ
- United American Indian Involvement CA
- Blackfeet Indian Tribe MT
- Ute Indian Tribe UT
- Puyallup Tribal Health Authority WA

#### **CMHS Child MH Initiative**

- Navajo Nation NM (1994-1999)
- Passamaquoddy Tribe ME (1997-2003)
- Sacred Child Project N.D. (1997-2003)
- Sault Ste. Marie Chippewa Tribe MI (1998-2004)
- Northern Arapaho Tribe WY (1998-2004)
- Oglala Sioux Tribe –SD (1999-2005)
- Yukon Kuskokwim Health Corp. AK (1999-2005)
- United Indian Health Services CA (2000-2006)
- Fairbanks Native Association AK (2002-2008)
- Choctaw Nation OK (2002-2008)
- Native American Hlth Ctr/Oakland CA (2003-2009)

- MH Service providers become visible participants in local Native community
- Thinking beyond 9-5 work in the office
- Home-based, school-based services
- Attending traditional ceremonies
- Participating in community gatherings
- Volunteering for "kitchen duty" at such events
- Shopping at community stores
- Owning or renting a home in the community
- Being "genuine" and respectful

- Location of MH services is integrated into Al/AN community facilities
  - Architecture and design of MH facilities reflect being part of community and Native culture
  - Sponsor open community events at the facility that is identified as the MH program
  - Services are also provided within tribal medical clinics, schools, community centers, Head Start centers and other places where people naturally gather to seek help
  - Normalize help seeking for MH as no different than other community services

- Partnership with MH service providers and traditional healers
  - Contract with, or hire traditional healers as part of MH service array
  - Develop community specific protocols in consultation with elders
  - Healers provide case consultation
  - MH providers make informed referrals to traditional healers and participate with client (as appropriate)
  - These efforts emphasize MH struggles as normal and treatable by the cooperation of traditional and western models

- Culturally specific public education efforts and social marketing campaigns targeted at a specific tribal community or population
  - Conduct focus groups to create local community definition of "mental illness" and "mental health"
  - Consult with tribal elders to identify local traditional concepts that are related
  - Northern California tribal MH program used the "brush dance" ceremony as a metaphor for helping those who need "healing" and created an awareness campaign with that

#### Minimize diagnosis and labeling

- Diagnosis is helpful for professionals and clients to understand what specific symptoms are being identified as needing treatment, but should not become a person's personal label or identity
- Emphasize that people have full lives, and are more than only their diagnostic label
- Move towards strength-based language rather than pathology
- Define mental health/mental illness as "temporary state of disharmony", "temporarily out of balance" or other culturally appropriate terms defined by the community

### Summary

- Great diversity in AI/AN population
- Traditional concepts of MH are based in the idea of balance and relationships
- Effective strategies to reduce stigma are closely tied to MH integration with the local culture and community
- Each AI/AN community has their own challenges with stigma
- Stigma reduction efforts should be community-based involving those who are directly impacted by mental health issues

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# Stigma Associated With Mental Illness in American Indian/Alaska Native (AI/AN) Communities"

Donna M. Grandbois, MS, RN

#### CONCEPT of MENTAL ILLNESS

- Prior to European contact, there was no AI/AN concept about mental illness.
- Native people often do not tend to see mental illness as separate from physical or spiritual illness.
- The mental, physical, and spiritual are all seen as influencing health.
- All must be considered when treatment is planned.

#### HOW WORLDVIEWS COLLIDE:

#### American Indian/Alaska Native

- Relational, Circular
- Mind, Body, Spirit/One
- Mystical/Acceptance
- Ceremonials/Rituals
- Tribal connectedness
- Spirituality & Balance
- Cooperation/Sharing
- Patience/Respectful
- Present oriented
- Herbs, plants, nature

#### Majority Culture

- Linear, point A to B
- Psyche is the Focus
- Scientific/Verification
- Psychotherapy
- Individualism
- Organized Religions
- Competition/Winning
- Assertive/Forceful
- Future oriented
- Psychopharmacology

#### WHO is the Al/AN client?

- Only 3 published community epidemiology studies exist in the literature.
- Western conceptualization of psychopatholgy of AI/AN people has been the focus of studies rather than their tremendous strengths & coping strategies.
- Studies that focus only on alcoholism & suicide among AI/AN people perpetuate stereotypes & fail to explore causation, or help to improve the well-being of AI/ANs.
- Media exploits the image & culture of AI/AN people, often painting a distorted understanding of AI/AN cultures.

## Diversity among AI/ANs

- Commonalities in beliefs & traditions, but profound background differences.
- Two AI/AN people might have greater differences than two Europeans from different countries.
- The Role of Deculturation & Reculturation
   & their influence on stigma.

## Origins of stigma of mental illness (MI) among various AI/AN tribal groups

- A form of supernatural possession
- A sign of imbalance with the rest of the natural world
- Persons with MI possess a special gift
- Mental disorder is a hopeless state, much like a terminal illness
- Sharing private thoughts is taboo & often intermingled with mistrust

## Hiawatha Asylum for Insane Indians: The 1<sup>st</sup> Federal Mental Hospital for an Ethnic Group

A mental health benchmark in AI/AN History "Kill the Indian, Save the man".

(Yellow Bird, P. (2001) @ www.mindfreedom.org/pdf/wildindians.pdf



"Native peoples generally do not have a notion of "insane" or "mentally ill." I have been unable to locate a Native Nation whose indigenous language has a word for that condition. The closest I can come is a word more closely aligned with "crazy," which means someone is either very funny, or too angry to think straight" p.4.

(Yellow Bird, P., (2001). @www.mindfreedom.org/pdf/wildindians.pdf

## Eyewitness's remember.....

- What Clara said: "Some would see that sign "asylum" and it would hurt them; some were heartbroken" (Stawicki, E.)."
- Dr. Samuel Silk, Clinical Director @ St. Elizabeth's (1929) recounts: "Three patients were found padlocked in rooms. One was sick in bed, supposed to be suffering from a brain tumor, being bedridden and helpless...a boy about 10 years of age was in a strait jacket lying in his bed...one patient who had been in the hospital six years was padlocked in a room and, according to the attendant, had been secluded in this room for nearly three years"

...Prof. Grob, Rutgers University: "What you had here was an institution you could only define as deviant. It wasn't doing what a lot of other hospitals did, if you go through state's records, the person running it had no contact with psychiatry"......

Grob: "Would not the United States, if it could be held liable at all, be liable in these cases for enormous damages? The records of the asylum itself show them to be perfectly sane. They are known to be perfectly sane, to the director of the asylum Dr. Hummer. But he assumed the position that these people were below normal - mentally deficient - and they should only be discharged after they were sterilized, and as he did not have any means of doing this, there was nothing left but to keep them there until"......

(Stawicki, E. Dec. 9, 1997)

## U. Of South Dakota history professor Herbert Hoover said:

- "the creation of the asylum most likely grew out of an ignorance of Indian culture; not an organized plot designed to confine sane Indians".
- how native Americans dealt with insanity prior to the arrival of whites. So we took western European strategies of dealing with insanity. It really was a well intentioned desire to accomplish cultural imperialism without killing Indian people. And this was a part of it" (Canton, SD).

## Double, Triple, & Quadruple "Whammy" Increase Stigma Several-fold

- Being American Indian/Alaska Native & Having a Mental Illness = a double whammy
- Ageism, Ethnicity, and Mental Illness= a triple whammy
- Poverty, Isolation, Lack of Resources further increase feelings of stigmatization= a quadruple whammy

## Treatment that is delivered could re-traumatize AI/ANs & provoke negative outcomes based on their:

- Boarding school experiences
- Previous history of trauma
- Fear & mistrust
- Daily struggles responding to poverty, disenfranchisement, alienation & racism

## Stigma on the reservation is expressed in the following

Ways:

- Stigma is maintained & perpetuated by close tribal communities & connectedness.
- Privacy is protected by denying the presence of mental illness, thereby maintaining the unspoken rule not to talk about mental illness.
- The ill person needing services will "try to handle their problems alone", so not to be a burden.

# Stigma is a major barrier to mental health care for AI/AN's.

Lack of socialization among clients:

Creates isolation and loneliness

Eliminates peer support

Disturbs self-esteem

# Mental Health Care is:

- Limited to acute, crisis-oriented out-patient services.
- Consists of pre-scheduled, hourly appointments in institutionalized settings.
- No resources for psychiatric stabilization or continuum of care directed at recovery.
- Often no Psychiatric hospitalization in AI/AN communities.
- Mental health programs operate @ 1/3 the budget necessary for minimal provision of care.
- Western treatment approaches are the norm & AI/AN culture is not typically incorporated.

# Mental Health Care Deficits:

- Personnel shortages
- Crisis orientation of care
- Limited prevention efforts
- System net-working & collaboration
- Family therapy interventions
- Family involvement with children/adolescents programs
- Parent aide programs
- Alcohol treatment programs

- Support groups
- Lack of internal resources, outside referrals
- Crisis intervention
- Psychiatric & psychconsultation
- Community mental health awareness
- Underutilization of services

# Efforts to Address Stigma Directed at AI/AN People with Mental Illness

- The cultural "blind spot" surrounding mental illness must be confronted & resolved.
- AI/ANs need to become educated about, own, & integrate their own history in this country.
- The "historical journey" of AI/AN people must be told & heard by other Americans. It must be written.
- American Indian & Alaska Native people need to find ways to assume their rightful place in American society.
- The United States of America must become "a good place to be an Indian or an Alaska Native."

# MODELS or APPROACHES to DECREASE STIGMA

- History Must Not Repeat itself: AI/ANs must have a voice in their own healing
- Care must be consistent with AI/AN Worldviews
- A Culture of Recovery must be created
- Survivors of Mental Illness & AI/AN Survivors (with or without diagnosed MI) may share a parallel road to recovery & wellness
- Empowerment Model of Recovery from Mental Illness @ http://www.power2u.org/pace\_manual.pdf
- Takini Network (means Survivor or to come back to life)
   http://www.whitebison.org



# Words are the most powerful drug used by mankind. Rudyard Kipling

Native Americans and Alaska
Natives have long been storytellers, their words and stories
need to be heard, so healing can
begin.

# Daniel Bill, Clinical Supervisor Yukon-Kuskokwim Health Corp.

When a child is born he is not a stranger to the community. The family tree of the newborn is known to his community. As the child grows they learn of his behaviors. The child learns of his limitations and is permitted to perform tasks he is able to accomplish. Limitations are imposed on his activities as he ages even through the physical adult age.

He is kept from performing some tasks; however, learning is encouraged by his members. He is excluded from most of the activities of his age group.



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## **Questions?**

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### Conclusion

Thank you very much for participating in the SAMHSA ADS Center conference call, "Overcoming Barriers and the Stigma Associated with Mental Illness in American Indian and Alaska Native (AI/AN) Communities."

The Resource Center to Address Discrimination and Stigma (ADS Center) is a project of the U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services.



# **Discussion Questions**

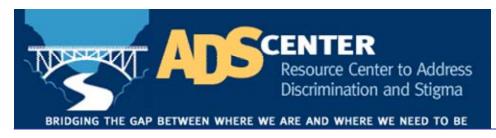
- 1. How are stigma and discrimination demonstrated within AI/AN communities and what is the impact of such stigma and discrimination?
  - a) Have we adequately incorporated tradition into contemporary treatment delivery mechanism?
  - b) If so, what successes have we experienced?
  - c) If not, why not? How should we begin?
- 2. What are some of the unique cultural characteristics within AI/AN communities, particularly regarding mental health issues?



# **Discussion Questions**

- 3. What can be done in Al/AN communities to reduce stigma and discrimination?
- 4. What are 2-3 key messages that non-Native service providers should hear in order to provide effective treatment/support?

Please feel free to use these questions as the basis for your own group discussion about stigma associated with mental illness in American Indian and Alaska Native communities.



### Resources

#### **Articles:**

The views expressed within these resources do not necessarily represent the views, policies, and positions of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, or the U.S. Department of Health and Human Services.

Mohatt, G. & S. Varvin (1998). "Looking for 'a good doctor': A cultural formulation of the treatment of a first nations woman using western and first nations methods." *American Indian and Alaska Native Health Research, 8(2)*: 79-97.

Rodenhauser, P. (1994). "Cultural barriers to mental health care delivery in Alaska." *Journal of Mental Health Administration*, 21(1): 60-70.

Yellow Horse Brave Heart, M. & L.M. DeBruyn (1998). "The American Indian holocaust: Healing historical unresolved grief." *American Indian and Alaska Native Mental Health Research*, 8(2): 56-79.

Yurkovich, E.E., J. Clarmont, & D. Grandbois (2002). "Mental health care providers' perception of giving culturally responsive care to American Indians." *Perspectives in Psychiatric Care*, 38(4): 147-157.



### Resources

#### On the Internet:

The views expressed within these resources do not necessarily represent the views, policies, and positions of the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, or the U.S. Department of Health and Human Services.

National Center for American Indian and Alaska Native Mental Health Research (http://www.uchsc.edu/ai/ncaianmhr/ncaiainmhr\_index.htm)

Native American Advocacy Project (http://www.sdnaap.org/)

National Indian Child Welfare Association (http://www.nicwa.org/)

National Alliance of Multi-Ethnic Behavioral Health Associations (http://nambha.org)